STATEWIDE COORDINATED STATEMENT OF NEED DOCUMENT (SCSN)
2000

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STATEWIDE COORDINATED STATEMENT OF NEED

BACKGROUND

On August 18, 1990, Congress enacted Public Law 101-381, the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act, honoring Ryan White, a teenager from Indiana with hemophilia, who died of AIDS at 18. Ryan White was instrumental in teaching the nation how to respond to the HIV/AIDS epidemic with hope and action rather than fear. The CARE Act provides funding to improve the quality and availability of care for people with HIV/AIDS and their families. The funds support low-income, uninsured or under-insured individuals and families.

The HIV/AIDS Bureau (HAB) of the Health Resources and Services Administration (HRSA) administers the funding. The flow of the CARE Act funds varies by title:

- Title I provides funds to eligible metropolitan areas (EMA) most severely affected by the epidemic, administered by the chief elected official or designee. The Norfolk EMA receives Title I funding. The Northern and a portion of the Northwest regions receive Title I funding as part of the Washington, DC, EMA.

- Title II provides funds to states and territories administered by the agency designated by the Governor. Since the inception of the Ryan White CARE Act, the Virginia Department of Health (VDH) has administered this funding in Virginia.

- Title III (B) funds are for early intervention services given to public and private non-profit entities. Central, Northern and Northwest regions receive this in Virginia.

- Title IV funds services to women, children, youth and families, and is administered by public and private non-profit entities. Central and Northern Virginia receive this funding.

- Part F of the CARE Act supports Projects of National Significance (SPNS) that develop innovative models of HIV/AIDS care, AIDS Education and Training Centers (AETC) and HIV/AIDS Dental Reimbursement Programs. Central Virginia and Northern Virginia have local performance sites of the Pennsylvania Mid-Atlantic AETC and the Medical College of Virginia (MCV) School of Dentistry administers a Dental Reimbursement Program.

The CARE Act was reauthorized in 1996 and 2000. The 1996 amendments require all grantees receiving Ryan White funding to participate in the development of a Statewide Coordinated Statement of Need (SCSN) document.

The goal of the SCSN is to foster collaboration and create effective linkages with all of the Ryan White funded, as well as other HIV-related programs, for the purpose of improving access and quality of care to people living with HIV/AIDS (PLWH/A) across the state of Virginia. The document is to identify the available services, accessibility of these services and critical gaps that prevent PLWH/A from receiving quality care. HRSA does not intend for the document to be a plan, but expects the SCSN to come up with broad goals to address the gaps in services according to specific variables affecting care in each region. HRSA expect states to use the document to apply for and use funding to support programs to fill the critical gaps.

The 1996 reauthorization language assigned the responsibility of coordinating the development of the SCSN to the administrative agency of the Title II funds. VDH developed the last SCSN in 1997. This is the second SCSN that Virginia has developed. The first SCSN was prepared subsequent to the SCSN meeting held on October 22, 1997. Ninety-four participants attended, with consumers representing 26%. Eight attendees who functioned as small group facilitators worked with VDH staff after the meeting to draft the SCSN report, which was reviewed by attendees and submitted to HRSA as required. Copies of the SCSN were shared with all Ryan White Titles so that it could be used in planning for each grant program. Some of the gaps identified in 1997 did not emerge as major issues in the current SCSN, which should indicate that progress has been made. These areas include lack of mental health/substance abuse services, need for housing, lack of child care/respite care, and need for permanency planning such as foster care

VDH coordinated the development of the 2000 SCSN with the help of a twenty member advisory committee with 50% representation by consumers. VDH set this up in July 2000. and it had representatives from the five regional consortia, all Titles, Housing Opportunity for People with AIDS (HOPWA), Department of Medical Assistance Services (DMAS), and the Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS). The theme for the 2000 SCSN was 100% Access with 0% Disparity. The date for the SCSN was set for October 12, 2000. The SCSN Planning Committee met twice a month to plan the meeting. Five hundred invitations were distributed to all programs funded by the Ryan White CARE Act, other states and federal programs and organizations providing services to PLWH/A, other stake holders, planning groups, community-based organizations, consumers, providers, public agencies and the Regional HIV/AIDS Resource and Consultation Centers (Centers of Excellence) that are state funded and provide clinical training to health care providers. Virginia chose to make the process as inclusive as possible.

The Ryan White Subcommittee of the HIV Community Planning Committee (HCPC) has the unique view of bringing service and prevention together. The suggestions and cooperation of this subcommittee proved invaluable as the meeting plans were formulated. In addition, every resource from the VDH Division of HIV/STD team was called to assist with the marketing and logistics of the meeting. The meeting was attended by 155 individuals of which 61 (39%) were consumers.

The morning sessions consisted of epidemiological data, overview and utilization of the 1997 SCSN and the current mission, reports from all grantees, reports from other agencies and reports from consumer groups that were involved in providing HIV/AIDS health care in Virginia. The program also included Dr. David Butcher, Director of Chase Bruxton Clinic and Assistant Professor at Johns Hopkins University in Baltimore. He delivered an HIV/AIDS update, as well as motivated the group to commit themselves to the development of the SCSN and improved care across Virginia.

For the afternoon portion of the SCSN, the planing group decided that instead of identifying the gaps in services and coming up with a plan, the gaps in each region would have been already identified. To achieve this, the five regional consortia combined all the need assessments and surveys done in 1999 and 2000 to come up with the 8 top unmet needs in the five regions. The eight small group facilitators were selected before the meeting and met to design an outline that would be used to facilitate the small groups. They discussed each unmet need, barriers to meeting that need and goals to break down the barriers. The group chose a recorder. This strategy saved much needed time for discussion and development of the goals. The meeting concluded with the small groups reporting to all the participants. The Advisory Committee and the eight facilitators met several times after the meeting to develop the SCSN document.

1. VIRGINIA BACKGROUND INFORMATION

Virginia is located south of Washington, DC, the nation's capital. It was founded at Jamestown, which is the first permanent English settlement in North America. The geography of Virginia is varied, ranging from dense urban centers to rural mountious areas. Virginia has a total land mass of 40, 815 square miles. According to 2000 statistical data, Virginia population is approximately 7,078,515 and is racially comprised as follows: White, 72.3%, Black, 19.6%, and persons reporting some other or 2 or more races 4%.

Virginia contains 95 counties, 40 independent cities, and 190 incorporated townships, with a variety of industries, including tobacco, chemical, shipbuilding, and farming as well as a number of Fortune 500 companies who make Virginia their headquarters.

2. EPIDEMIOLOGICAL DATA

A. STD Trends

The prevalence of Chlamydia is continuing to increase in Virginia, especially in adolescents. The number of cases of Chlamydia in the 15-19 age group has increased from 4,896 in 1996 to 6,176 in 2000. The number of cases of Chlamydia in the 20-24 age group is also increasing. (Division of HIV/STD, VDH).

The incidence of gonorrhea is continuing to hold steady in the 15-19 and 20-24 age groups at about 2500-3000 cases in each group each year. (Division of HIV/STD, VDH).

The incidence of early syphilis is decreasing in these populations. Health Department staff believes the marked decrease in early syphilis is due to the aggressive syphilis elimination program that is occurring in Virginia.

The data shows that despite a dramatic decrease in the incidence of early syphilis, there is not a corresponding decrease in other STDs. This leads to a concern that risky behavior is not changing in this population which could lead to increase in the number of HIV/AIDS in persons under 24 in the Commonwealth of Virginia.

B. HIV Trends

There has been improvement in the incidence of HIV in the Commonwealth of Virginia since 1996. The total number of new cases reported has decreased from 998 in 1997 to only 804 in 2000. However, the impact of the epidemic is still felt with an increasing number of persons living with HIV in the Commonwealth, about 13,000 persons in 2000.

There has been a change in the face of the epidemic. The proportion of African-Americans with HIV has decreased from 71.3% in 1997 to 68.3% in 2000. The proportion of Hispanics has increased from 1.5% in 1997 to 4.9% in 2000. The proportion of other races has also increased from 1.5% in 1997 to 2.7% in 2000. This reflects the increased outreach and testing in the immigrant populations. (Division of HIV/STD, VDH)

Morbidity of HIV in Virginia by Race 1997-2000

	1997	1998	1999	2000
African-American	71.3%	68.7%	69.2%	68.3%
White	24.1%	25.6%	25.8%	24.1%
Hispanic	3.0%	3.8%	4.1%	4.9%
Other	1.5%	1.9%	0.9%	2.7%

(Division of HIV/STD, VDH)

The proportion of females infected with HIV has also increased with the largest increases found in the Hispanic and other populations. Hispanic females' incidence increased from 2.4% in 1997 to 6.4% in 2000 and other races from 1.0% to 2.8%.

Morbidity of HIV in Virginia Females 1997-2000

	1997	1998	1999	2000
African-American	83.4%	79.0%	82.7%	76.9%
White	13.2%	17.7%	13.5%	13.9%
Hispanic	2.4%	1.2%	3.8%	6.4%
Other	1.0%	2.0%	0.0%	2.8%

Decreases in HIV morbidity are found in all regions of the state except Eastern, which increased. The highest overall incidence continues to be found in the Eastern region with its large population centers and military bases.

Though the 35-39 age group still accounts for the largest number of cases, there is an increase in the over 50 population with 14.6% of the population diagnosed with either HIV or AIDS in this age group.

HIV risk distribution continues its previous pattern. Men who have sex with men (MSM) continue to be the most represented category with heterosexual contact the next most frequent. The largest percentage of cases in the Commonwealth of Virginia report NO Identifiable Risk (NIR), 38.2% of cases in 2000. Virginia has instituted a program to follow-up with cases listed in NIR in an attempt to better categorize these cases.

Morbidity of HIV in Virginia by Most common Transmission Categories

	1998	1999	2000
MSM	32.2%	31.6%	27.4%
IDU	11.2%	8.7%	8.8%
MSM&IDU	2.7%	2.0%	1.9%
NIR	25.6%	29.9%	38.2%

Since the mandatory testing of all pregnant women for HIV was begun in the 1990's there has been a dramatic decrease in the perinatal transmission of HIV. In 2000, there were no cases of perinatal transmission and 95% of all pregnant women who tested positive for HIV were given AZT during their pregnancy.

C. AIDS Trends

African American males continue to account for the majority of all cases of AIDS in Virginia, 46% in 2000. However, the percentage of females in population is continuing to increase from 20.6% in 1997 to 24.6% in 2000. African American females were 17% of the total, so the impact of the epidemic on the African American community continues to be severe, 64% of all the cases. As with HIV, the proportion of cases in the Hispanic community is also increasing, from 3.9% in 1997 to 4.7% in 2000.

Morbidity of AIDS in Virginia by Race in 1997-2000

	1997	1998	1999	2000
African-American	62.5%	66.0%	66.3%	63.3%
White	32.8%	30.8%	28.7%	30.5%
Hispanic	39.%	2.5%	4.5%	4.7%
Other	0.8%	0.6%	0.4%	1.7%

The age distribution of cases of AIDS remains fairly constant with the 35-39 year olds accounting for the largest percentage of cases. There continues to be concern that the cases of AIDS identified in the 20-29 year olds were infected during their adolescence. There are 302 cases of AIDS in this age range in 2000. However, over the last 5 years there have been less than 50 new cases of HIV identified each year in 10-19 year olds.

REGIONAL NEEDS ASSESSMENTS

As described earlier in this document, 5 regional consortia combined all the 1999 and 2000 needs assessment, surveys and focus groups to come up with the top 8 unmet needs in each region. The identified needs were as follows:

8= Top Priority 1 = Least Priority

Northern Virginia:

8. Housing Assistance
7. Other Direct Emergency Financial Assistance
6 Dental Care (Restorative)
5. Food Vouchers
4. Non-HIV Medical Care and Medications, e.g., for Hepatitis C.
3. Baby sitting/Respite Care
2. Employment Counseling/Training
1. Transportation

Eastern Virginia

8. Direct Emergency Financial Assistance
7. Housing Counseling
6. Food
5. Medications
4. Dental Care
3. Housing Assistance
2. Referrals
1. Health Education

Central Virginia

8. Dental Care
7. Help to receive Government Benefits
6. Alternative Therapies (Massage, Acupuncture, Herbal)
5. Access to Medications.
4. Information to HIV Support Services
3. Support Groups/One-on-One Counseling (with HIV + personnel)
2. Rent/Utilities Emergency Assistance
1. Help with Legal Assistance

Southwest Virginia

8 Primary Medical Care
7. Dental Services
6. Medications
5. Laboratory Services
4. Transportation Costs
3. Case Management/Outreach Worker Services
2. Mental Health Counseling
1. Child Care/Respite Care

Northwest Virginia

8. Transportation
7. Direct Emergency Financial Assistance
6. Housing
5. Dental Care
4. Medication Cost
3. Counseling Services
2. Food
1. Advocacy

Aggregate Top 8 State HIV Needs

8. Dental Care (30)
7. Emergency Financial Assistance (25)
6. Medications (24)
5. Case Management/Referrals (dissemination of information about benefits, and services available) (16)
4. Food (13)
3. Housing Assistance (9)'
2. Primary Medical (8)
1. Health Education/ Complimentary Therapies (7)

An important difference between needs of PLWH/A and unmet needs had to be made to avoid confusion. Primary Care is one of the top needs but did not come up as an unmet need since there were adequate primary care sites, but transportation to them was an unmet need. Each unmet need by region was given a number from 1-8, 8 being the first need and 1 being the last for each region. The numbers were then added to come up with the top eight unmet needs across the regions.

Common Barriers To HIV Care Identified At The SCSN Meeting And Goals To Overcome The Barriers.

BARRIERS

- Poverty.
- Unemployment.
- Lack of Insurance.
- Large co-pays for services and medications with insurance.
- Homelessness - lack of structure and refrigerator for meds.
- Ineligibility for Medicaid benefits - Destabilization of public health services due to managed care.
- Ineligibility for Ryan White Services and AIDS Drug Assistance Program (ADAP). - current eligibility is at 250% of the Federal Poverty Level (FPL).
- Lack of quick reimbursement process.
- Lack of qualified providers.
    a. Lack of knowledge on needs of HIV patients.
    b. Do not want to be known as "HIV " providers.
    c. Low reimbursement rates (compared to insurance).
    d. Request for Proposal (RFP) for funding not reaching potential providers.
- Patients' distrust of providers.
- Lack of culturally competent, racially sensitive providers.
- Lack of translation services.
- Non-compliance with appointments and medications.
- Untreated other co-morbidities - substance abuse (SA) and mental illness (MI).
- Unknown sero status.
- Fear of disclosure and avoidance of care among individuals with HIV due to stigma.
- Lack of knowledge of programs among low income HIV positive persons
- Lack of transportation
- Lack of childcare.

GOALS TO OVERCOME THE BARRIERS

- Fund vocational rehabilitation/counseling programs.
- Fund or identify programs to pay insurance premiums for those temporarily out of work
- Supplement other housing funds such as Housing for Patients With AIDS (HOPWA).
- Raise Ryan White eligibility from 250% to 300% of the Federal Poverty Level.
- Identify and establish linkages to indigent care for patients who do not qualify for Medicare or Ryan White services.
- Provide funds to pay the large co-pays for medications and services for insured patients.
- Institute quicker reimbursement process for services.
- Fund more case managers with better salaries.
- Facilitate training and education for providers on standards of care in meeting special needs of HIV patients, cultural competence and racial sensitivity and case management standards. Work with the Virginia Department of Health and the Regional HIV/AIDS Resource and Consultation Centers that are state funded for HIV provider education.

- Provide incentives, funding money and technical assistance (TA) to providers willing to treat HIV patients.
- Fund nurse practitioners in areas where doctors are unavailable.
- Fund a marketing coordinator position (staff person) to identify HIV providers and services and enable RFPs to reach more potential providers.
- Fund translation services for both dialogue and literature.
- Fund devices that alert patients regarding appointments and medications, (example: Medimom)
- Fund adherence counselors.
- Fund transportation and child care services.
- Establish linkages for treatment of co-morbidities - substance abuse and mental illness.
- Fund more Prevention Case Management Programs (PCM) to monitor patients with multiple problems.
- Hold HIV clinics and testing along with other clinics to avoid the stigma of being identified as a HIV patient.
- Fund clinic hours outside the working hours.
- Public (multimedia) education to overcome stigma associated with HIV.
- Fund incentives for testing and getting HIV individuals into care - easier access, non-invasive testing (Orasure), rapid testing (when available).
- Fund peer education and outreach - more trust and better response.
- Involve dental and medical schools/mobile units for care - mutual benefits for patients and students.
- Co-fund positions and services with other Ryan White titles and dental reimbursement programs.
- Develop and update a resource list for patients and providers and make it easily available (VDH hotline).
- Fund and/or identify mechanism to provide transition services when patient move from state to state.
- Fund quality primary prevention programs for HIV plus individuals.

CONCLUSION:

The steady expansion and changed demographics of the HIV epidemic, as well as improved survival time for people living with AIDS, are placing increased stress on state and local health care systems, CBOs and families. In the last twenty years the HIV/AIDS epidemic has claimed over 420,000 American men, women and children. Today, the Centers for Disease Control and Prevention estimates that there are currently between 800,000 to 900,000 persons living with HIV in the United States, with 400,000 new infections annually. A forum such as the SCSN that provides opportunity for crucial dialogue between consumers and providers helps to identify actual unmet needs, barriers to meeting those needs and goals to break down the barriers.

This SCSN document was sent to every participant before it was finalized and includes his or her feedback. Thus, the finished document should be a very useful tool for planning and funding HIV care in Virginia. The document will be made available to funding agencies that will enable them to identify HIV needs that have to be addressed.